

# BREAST CANCER SURVIVORSHIP REHABILITATION INITIATIVE

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## COMMUNITY REPORT

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SUPPORT FOR THE BREAST CANCER SURVIVORSHIP REHABILITATION INITIATIVE COMES FROM THE WOMEN'S BREAST HEALTH FUND OF THE COMMUNITY FOUNDATION OF GREATER BIRMINGHAM AS PART OF AN EFFORT TO IMPROVE THE QUALITY OF LIFE FOR WOMEN WHO ARE BREAST CANCER SURVIVORS AS WELL AS THEIR LOVED ONES.



# Breast Cancer Survivorship Rehabilitation Initiative

## Community Report

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## Executive Summary

In 2015, there were an estimated 3 million breast cancer survivors in the United States. As early detection and treatment options improve for breast cancer patients, the number of breast cancer survivors will increase by nearly 30 percent in the next decade to approximately 3.78 million. Breast cancer is the number one cancer diagnosis in females, and the female breast cancer mortality rate in Alabama is 23.4 percent, marginally higher than the US rate of 23.3 percent (Alabama Cancer Facts and Figures). Survivors report fair to poor health versus adults without a history of cancer. Survivors face psychological, physical, medical, social, spiritual and cultural challenges as a result of their diagnosis and treatment. Recognizing cancer survivorship as a distinct phase of cancer care deserves ongoing attention from all healthcare providers.

The Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) conducted an assessment of breast cancer survivorship services in the Greater Birmingham area, including Blount, Jefferson, Shelby, St. Clair, and Walker counties, over the course of four (4) months. Project staff disseminated surveys and conducted one-on-one interviews with self-identifying respondents. Following the conclusion of both the surveys and interviews, discussion groups were held. An Ad Hoc Committee was then formed from a group of community leaders and experts in the field of cancer survivorship to review the data and provide feedback. The BCSRI also conducted interviews with the directors of 12 cancer survivorship programs throughout the country. The aggregated data was presented in monthly meetings to a leadership team consisting of executive level hospital administrators in the Greater Birmingham area.

Key findings include:

- Survivors seek advice and information from other survivors above any other source, including healthcare professionals and the internet.
- The need for psychological counseling, support groups, and mental and emotional support for survivors, their families and their co-survivors was emphasized by both healthcare professionals and survivors.
- Healthcare professionals and survivors agree that physical problems of most concern are:
  - Fatigue
  - Memory/Concentration
  - Appearance
- Gaps in Physical Care include:
  - Nutrition
  - Exercise
  - Physical Therapy
  - Lymphedema Counseling
- There is a lack of awareness of programs and resources available amongst survivors/co-survivors. Healthcare professionals are much more knowledgeable than survivors/co-survivors on what resources are available.
- There is a need for cultural sensitivity in breast cancer care.

This report will summarize the data and serve as a resource to develop programs throughout the community to provide breast cancer survivorship care and patient advocacy. Next steps include developing the infrastructure needed to build a survivorship program that will meet the needs of breast cancer survivors in the Greater Birmingham area, and potentially become a model that can be replicated for other cancer types and diseases or for breast cancer survivors in other communities.

## Introduction

As early detection and treatment options improve for breast cancer patients, the number of survivors<sup>1</sup> increases. In a recent report, The Institute of Medicine noted that many breast cancer survivors become lost in the transition from cancer patient to cancer survivor. Recognizing cancer survivorship<sup>2</sup> as a distinct phase of cancer care deserves ongoing attention from cancer and other healthcare providers. Due to decreased funding for support services, individual health care providers often find it challenging to offer a full range of rehabilitation services once cancer survivors complete their treatment.

With funding from the Women's Breast Health Fund, the Breast Cancer Survivorship Rehabilitation Initiative (BCSRI) is a collaboration of the Community Foundation of Greater Birmingham, Baptist Health System, Brookwood Medical Center, St. Vincent's Health System, Trinity Medical Center, UAB Medicine and UAB School of Nursing.

Our primary goal is to evaluate, discern, and develop a community-based, patient centered comprehensive program to assist survivors and their families who have faced a breast cancer diagnosis. It is our vision that this program will:

- Provide proactive rehabilitation<sup>3</sup> in order to reduce comorbid conditions such as heart disease, osteoporosis, etc.
- Promote physical health and quality of life<sup>4</sup> through lifestyle intervention programs
- Eliminate gaps and fragmentation in care following breast cancer treatment
- Reduce costs for both the institutions and care recipients
- Provide a model for breast cancer survivorship that can be replicated for other diseases

The BCSRI conducted an evaluation of breast cancer survivorship services in the Greater Birmingham area, including Blount, Jefferson, Shelby, St. Clair, and Walker counties, over the course of four (4) months (January 2015- April 2015).

The first phase of data collection was assessing community need through two separate surveys. One survey was designed specifically for Survivors/Co-Survivors,<sup>5</sup> and the other for Healthcare Professionals. A total of 235 responses were received.

### Survivor/Co-Survivors (168)

76.28 percent identified as White

23.72 percent identified as African American

### Healthcare Professionals (67)

81.97 percent identified as White

14.75 percent identified as African American

3.28 percent selected "Other", or Undisclosed

<sup>1</sup> A Survivor is a person living with breast cancer from the time of diagnosis through end of life (Komen).

<sup>2</sup> Survivorship is the emotional and physical health, life and care of a breast cancer survivor from the time of diagnosis until the end of life (Komen).

<sup>3</sup> Cancer Rehabilitation is a program that helps people with cancer maintain and restore physical and emotional well-being. Cancer Rehabilitation is available before, during and after cancer treatment (Komen).

<sup>4</sup> "Quality of life" is the term used to describe a person's overall well-being. It includes: mental health, physical health, ability to perform daily roles, sexual function, absence of symptoms (such as pain and fatigue) (Komen).

<sup>5</sup> A Co-Survivor is someone who lends support to someone diagnosed with breast cancer. Co-Survivors may include family members, spouses or partners, friends, health care providers and colleagues (Komen).

## Introduction (continued...)

The goal was to evaluate survivorship services for survivors in all stages of life, in a five (5) county area: Jefferson, Shelby, Blount, St. Clair, and Walker County. The respondents by county are as follows:

### Survivor/Co-Survivors

71.43 percent from Jefferson County  
14.29 percent from Shelby County  
5.95 percent from Blount County  
4.17 percent from St. Clair County  
4.17 percent from Walker County

### Healthcare Professionals

62.69 percent from Jefferson County  
22.39 percent from Shelby County  
1.49 percent from Blount County  
5.97 percent from St. Clair County  
5.97 percent from Walker County  
2.99 percent from Other Counties

The response rate of the Survivor/Co-Survivor Survey is reflective of the breast cancer incidence rates in all five counties (Alabama Cancer Facts and Features 15-25).

Respondents from both surveys were mostly female at 84 percent, with 7 percent male and 9 percent undisclosed. Of the survivors that participated in the survey, 47 percent finished treatment more than 5 years ago while 53 percent were newly diagnosed, currently in treatment, or those who completed treatment less than 5 years ago.

Project staff conducted one-on-one interviews with self-identifying respondents. 25 total interviews were conducted, 76 percent (19) were with survivors/co-survivors and 24 percent (6) were with healthcare professionals.

Discussion groups were held following the conclusion of both the surveys and interviews with a total of 26 participants. Five (5) Survivor/Co-Survivor Discussion Groups were conducted with different target populations. One (1) discussion group was conducted with healthcare professionals.

An Ad Hoc Committee was formed from a group of community leaders and experts in the field of cancer survivorship. The purpose of the Ad Hoc Committee was to review all the data from each of the Assessment tools and provide feedback on program recommendations. Members of the committee represented a wide range of specialties, including physical therapy, counseling, patient navigation<sup>6</sup>, nursing, and exercise therapy. Caregivers and a representative from the National Cancer Institute were also included.

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<sup>6</sup> Patient navigation is a patient-centric healthcare service delivery model. Patient Navigators are people who take individual patients through the continuum of healthcare as it pertains to their specific disease, ensuring that any and all barriers to that care are resolved and that each stage of care is as quick and seamless as possible (Harold P. Freeman Navigation Institute).



### **Introduction (continued...)**

BCSRI conducted interviews with the directors of 12 survivorship programs throughout the country. There are a number of models that exist to address late effects of adult onset cancer. And each program differs in focus and in organization. However, from the interviews with the directors of each survivorship program, information was compiled on best practices and commonalities.

- Nurse-Practitioner Led
- Prehabilitation
- Distress Screening and Assessment
- Physical Therapy and Lymphedema Services
- Survivorship Care Plan and Treatment Summary provided to the patient, general practitioner, and oncologist
- Part of the continuum of care
- Includes referrals to Integrative Medicine including:
  - 1) Nutrition
  - 2) Exercise
  - 3) Massage Therapy/Acupuncture
  - 4) Mindfulness/Meditation
  - 5) Psychosocial Support

An assessment of the health systems' cancer services was conducted at each of the partnering institutions. The hospital administrators and project team had difficulty measuring the services offered specifically for breast cancer patients in regards to survivorship because of differing codes and electronic medical records systems. This was particularly difficult in health systems that refer to private physician practices. Comparable data was not able to be accurately collected.

The data from each of these sources was then aggregated and presented to a leadership team comprised of executives from each of the community partners (Baptist Health System, Brookwood Medical Center, St. Vincent's Health System, Trinity Medical Center, UAB Medicine, UAB School of Nursing, and The Community Foundation of Greater Birmingham).



## Quality of Life Domains

The data in this report has been organized into Quality of Life domains, as established by The George Washington University and the American Cancer Society and adapted from the IOM report, *Lost in Transition* (2006), (National Cancer Survivorship Resource Center 1).

### Psychological

- Social Support
- Matched peer survivor support
- Coping Strategies to deal with fear of recurrence, anxiety and depression

### Physical

- Managing long-term/late effects (i.e. fatigue, pain, appearance)
- Interventions for health behavior change (i.e. diet, exercise, smoking cessation, screenings)

### Medical

- Communication with physicians
- Adequate communication among physicians/specialists
- Transition back to primary care setting

### Social

- Respite services to alleviate caregiver burden
- Financial assistance programs
- Programs to ameliorate employment problems

### Spiritual

- Spiritual counseling
- On-Site Chapel/Meditation Room
- Addressing and integrating spiritual needs into patient care

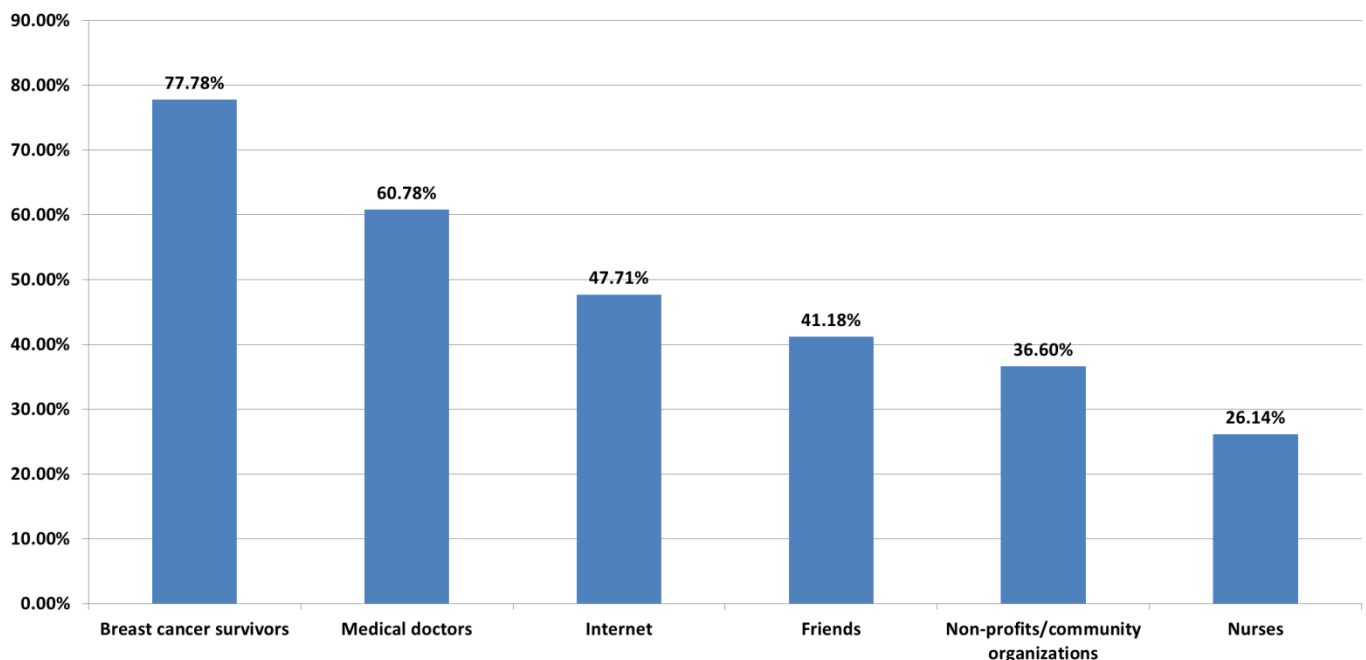


## Psychological

The desire for psychological treatment may not end when medical treatment does. In fact, emotional recovery may take longer than physical recovery and is sometimes less predictable. Although societal pressure to get everything back to normal is intense, breast cancer survivors need time to create a new self-image that incorporates both the experience and their changed bodies. Psychological needs are classified as needs that include aspects of social support, peer survivor support and coping strategies to help deal with anxiety, depression and the fear of recurrence. The need for psychological counseling, support groups, and mental and emotional support for survivors, their families and their co-survivors was emphasized by both healthcare professionals and survivors.

One finding of particular interest was that survivors seek advice and information from other survivors above any other source. In fact, more than 77 percent of survivors seek advice from other survivors. While survivors trust their physicians and utilize the internet for information, survivors are going to other breast cancer survivors for the majority of their information including advice on treatment decisions/protocols and medical teams (figure 1).

**Figure 1. Where is someone in your community most likely to go for BREAST CANCER SURVIVORSHIP information?**



Although survivors identified many supportive services they desired, many said they do not want to return to the health systems where they were treated for those services because health systems are associated with a place of trauma.

*“Survivors usually don’t want to return to the hospital to receive survivorship services after they have completed treatment. Generally survivors find the hospital to be a point of trauma.”*  
- Discussion Group Participant

### Psychological (continued...)

To help enhance their coping strategies, ad hoc committee members suggested that survivors are experts in their day to day lives and should be empowered, involved and included in the process of treatment and survivorship care.

*“Healthcare professionals cannot forget that while they are busy telling survivors how they are going to be supported, survivors are experts in their own lives. Empower survivors and give the control back to them by reminding them of this.”*

*- Ad-Hoc Committee Member (Marriage and Family Counselor)*

## Physical

Once very active, breast cancer survivors may now feel tired; their diet may have to change significantly; to decrease chances of recurrence, they may be embarking on their first exercise regimen; and, they may be suffering from limited mobility and/or lymphedema due to their treatment. All of these changes can negatively impact their recovery and chances for recurrence. Physical rehabilitation and exercise contribute to the long-term prognosis and health of breast cancer patients. The Physical Quality of Life Domain encompasses a need for care of a patient's physical being. For example, help managing the long-term/late effects of cancer treatment on the physical body i.e. fatigue, pain, heart, diet, exercise, smoking cessation and screenings fall in this domain.

The most significant gaps in the physical care of survivors include:

- Exercise which impacts overall health and recurrence risk
  - Less than 10 percent of cancer survivors are active during treatment (Kerry et al. 248).
  - Only 20-30 percent of cancer survivors are active after treatment, which means that the majority of survivors will not get the full benefit of consistent physical activity (Kerry et al. 248).
  - Studies show that post-diagnosis physical activity is associated with a 24 percent lower rate of recurrence and a 34 percent lower rate of mortality (Kerry et al. 248).
- Nutrition
  - Dietary pattern is important for overall survival of breast cancer survivors
  - Studies show that those on a Western diet have poorer overall survival in comparison to those who had a dietary pattern consisting of high amounts of fruits, vegetables and whole grain (Kerry et al. 248).

***“Patients are more likely to follow through with good nutrition and exercise if the importance is discussed at the beginning of treatment or before treatment begins.***

***- Physician***

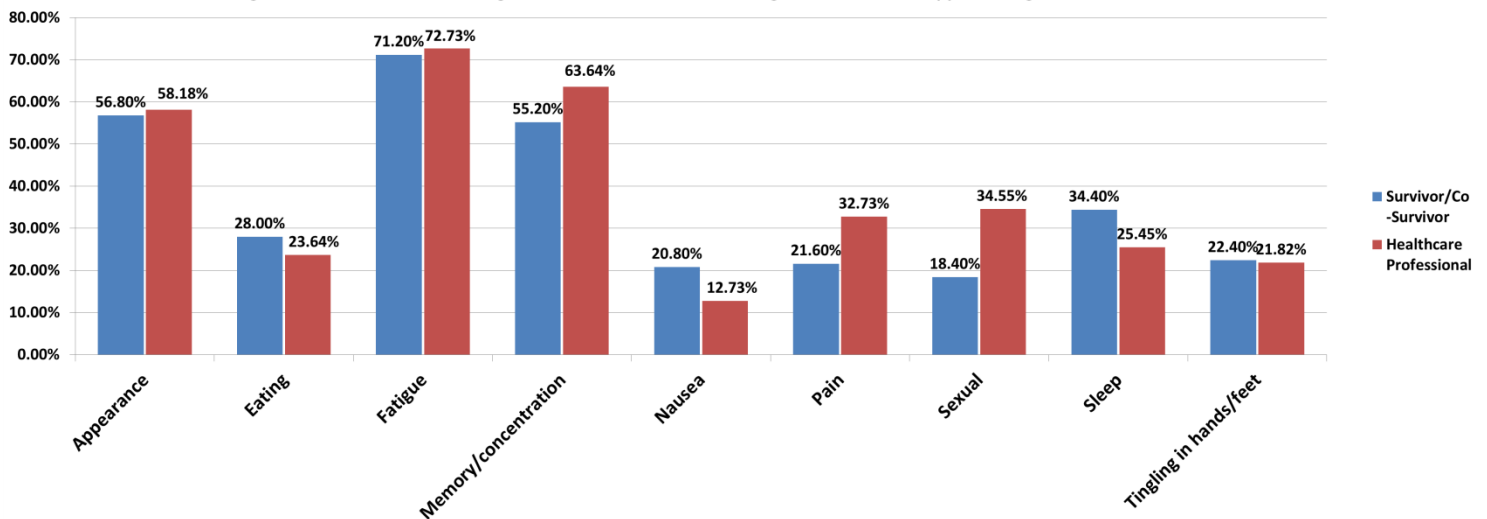
- Physical Therapy and Lymphedema Counseling
  - Insurance reimbursement of prehabilitation services (including pre-physical therapy and lymphedema counseling prior to the identification of lymphedema) is not mandated in the state of Alabama (Silver 4).

## Physical (continued...)

Healthcare professionals and survivors agree that physical problems of the most concern to survivors are (figure 2):

- Fatigue
- Memory/Concentration
- Appearance

Figure 2. Which of the following PHYSICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors?



- 71 percent of survivors/co-Survivors and 73 percent of healthcare professionals stated that fatigue remains a problem throughout treatment and beyond for many breast cancer survivors (figure 2).
- 55 percent of survivors /co-Survivors and 64 percent of healthcare professionals stated that memory and concentration problems are in high need for support. Cognitive issues can be extremely frustrating and while it is commonly referred to as “chemo-brain”, it is actually a much more complicated issue (figure 2).
- While there are few resources aimed at addressing appearance in breast cancer survivors during treatment, 57 percent of survivors and 58 percent of healthcare professionals agree that appearance throughout survivorship needs greater support.

## Medical

Medical needs consist of a survivor's needs when dealing with their medical teams and health systems, including communication with physicians, adequate communication among physicians/specialists and transitioning back into the primary care setting.

*“What would be great for me, would be to have someone help me navigate and show me what I need to do, and help me choose what’s best for me.”- Survivor*

Navigation services are services designed to empower the patient, provide resources and help patients navigate the complex world of medical systems (Wells et al. 113). The desire for navigation services was a consistent theme brought up in one-on-one telephone interviews and the discussion groups. Regardless of education or socio-economic background, survivors emphasized the need for these services from point of diagnosis through the balance of life.

34.96 percent of breast cancer survivors surveyed received a phone call (figure 3) informing them of their cancer diagnosis and 66 percent of women are given this diagnosis by a Surgeon (figure 4). These calls are often times made at night after hours, and the patient may or may not be given a referral or told what their next steps will be. If the call is made on a Friday evening, the patient has several days and nights ahead of them before they can receive any sort of support or get any questions answered.

Figure 3. When you were advised of your diagnosis, how were you told?

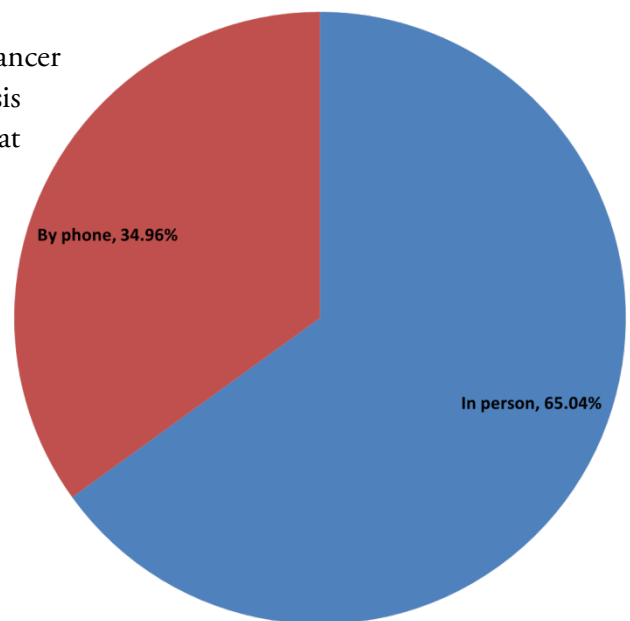
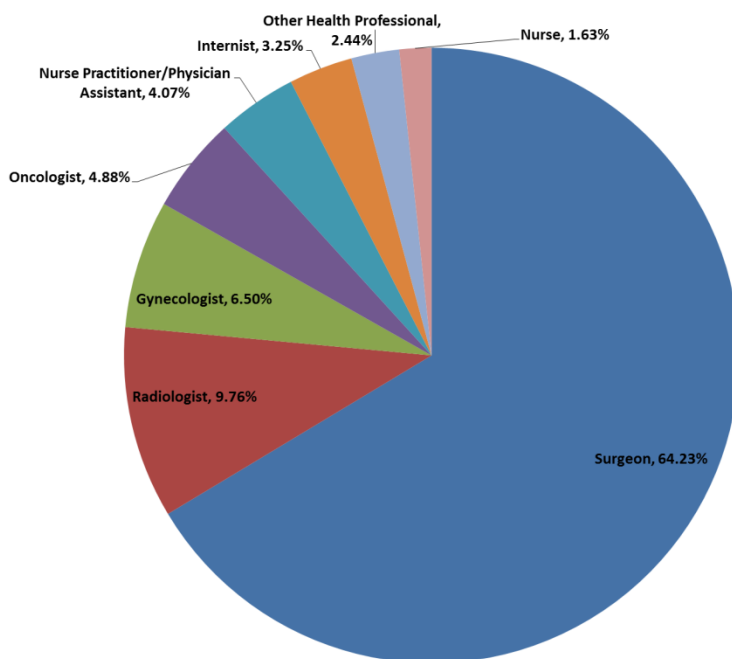


Figure 4. Who advised you of your diagnosis?

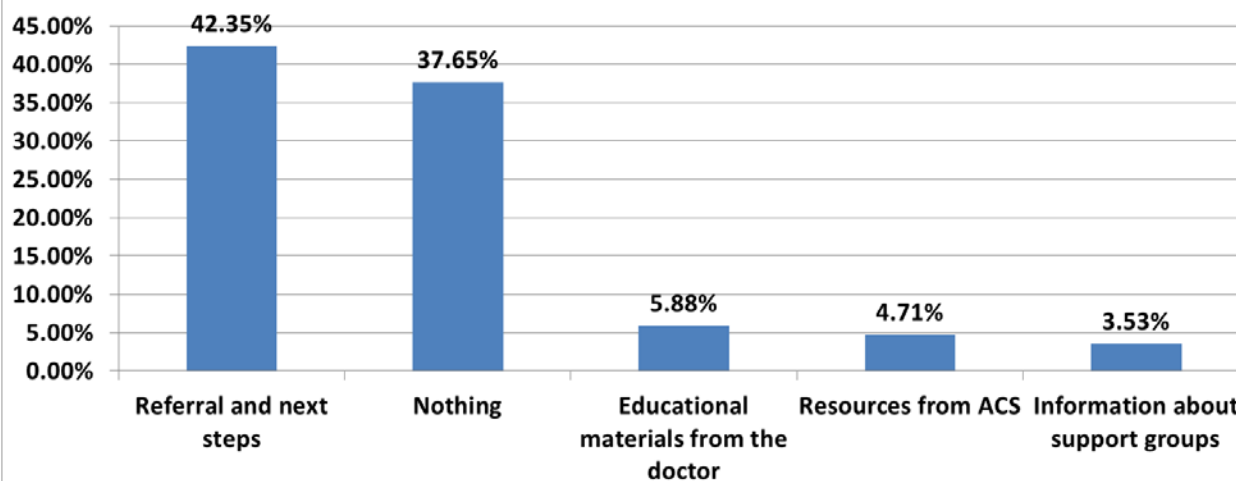


- Patients turn to friends/neighbors/survivors for information (figure 1). This information, depending on the source, may or may not be reliable and/or accurate.
- There is a lack of consistency in how newly diagnosed survivors are introduced to members of their medical teams (figures 3 and 4).

## Medical (continued...)

- 37.65 percent of survivors stated that they were not offered any resources after diagnosis (figure 5).

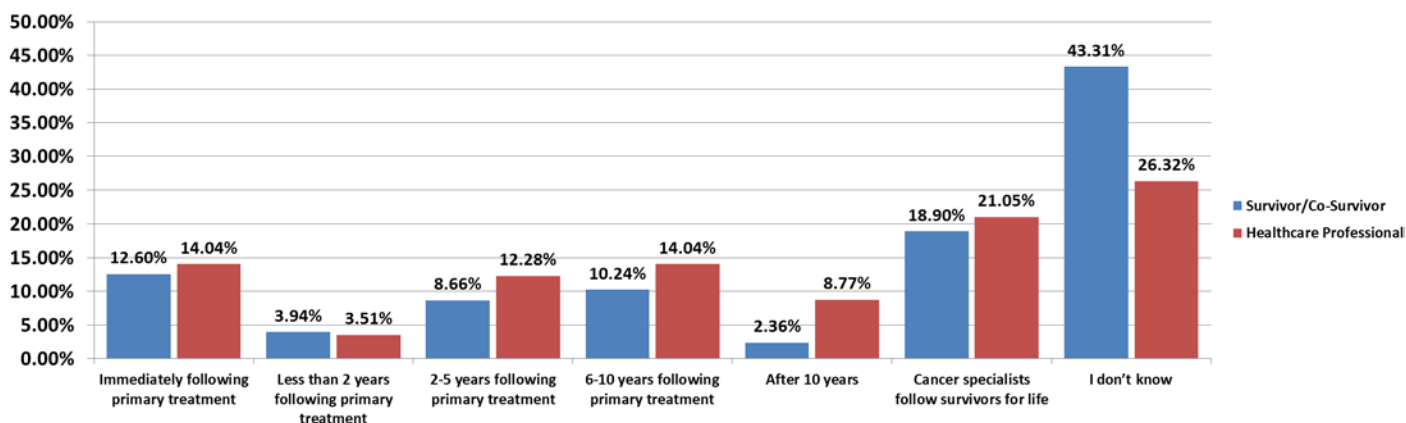
**Figure 5. When you were advised of your diagnosis, what resources if any, were you offered?**



As healthcare moves toward becoming more patient centered and treatment protocols reflect more individualized care, survivors often perceive this as a lack of consistency in how breast cancer is treated. This can cause undue anxiety for the patient, especially when they are not immediately made aware of their next steps.

Another indicator of the inconsistency in medical communication relates to referral back to primary care physicians. 43.31 percent of survivors/co-survivors and 26.32 percent of healthcare professionals surveyed do not know when a survivor is referred to/back to a general practitioner, or who “owns” the patients’ follow-up care (figure 6).

**Figure 6. In your community, when are breast cancer survivors referred back to their primary care physician for health care and cancer surveillance?**



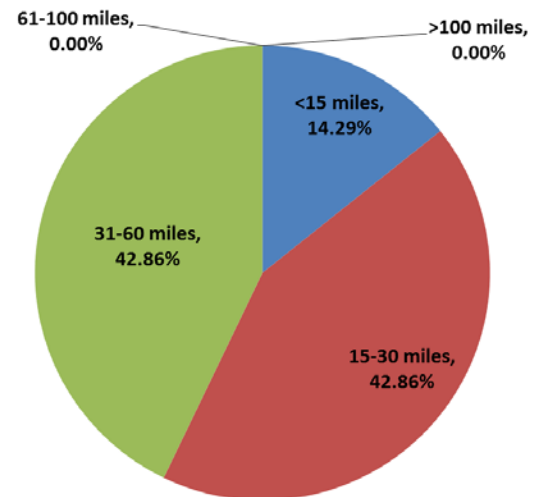


## Social

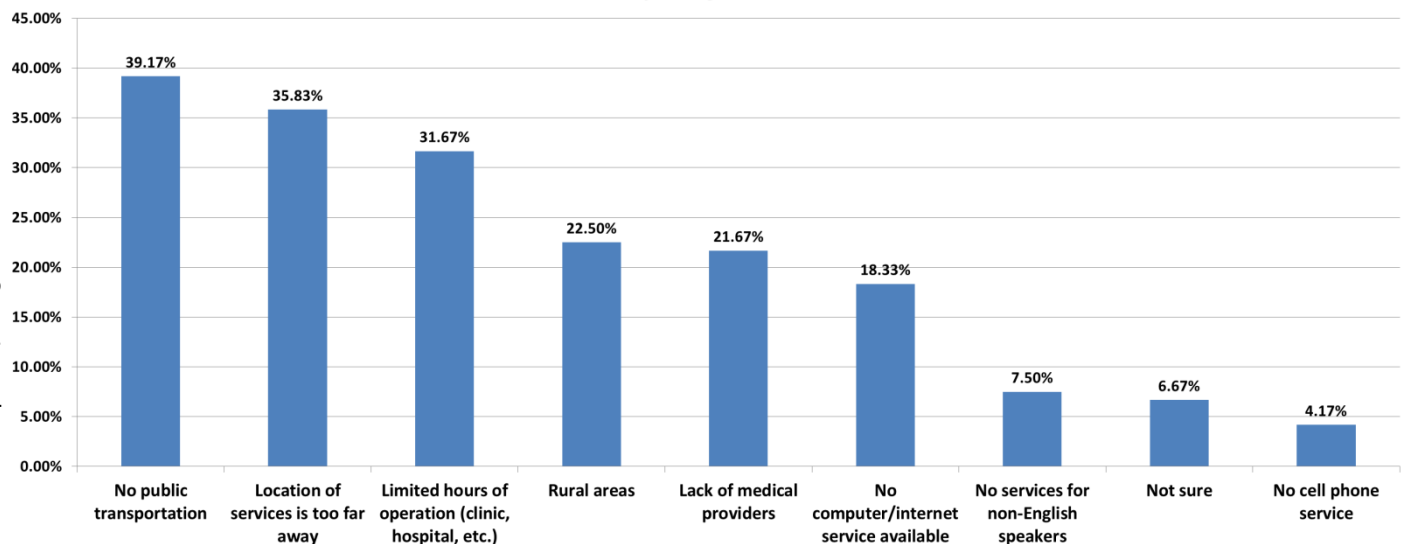
Social needs address a survivor's need for help addressing practical issues. This domain contains services that can assist survivors with practical problems such as, transportation, respite services to help alleviate caregiver burden, financial assistance programs and programs to ameliorate employment problems.

Accessibility is a major challenge to survivors: 58.33 percent of survey respondents live 30 miles or greater from a breast cancer treatment center (figure 7). This, along with the lack of reliable transportation and limited hours of operation, make managing work and child care very difficult (figure 8).

**Figure 7. How far away is the closest community that has BREAST HEALTH AND DIAGNOSTIC SERVICES available?**



**Figure 8. Which of the following are obstacles and barriers to breast cancer survivorship care in your community in regards to ACCESS?**

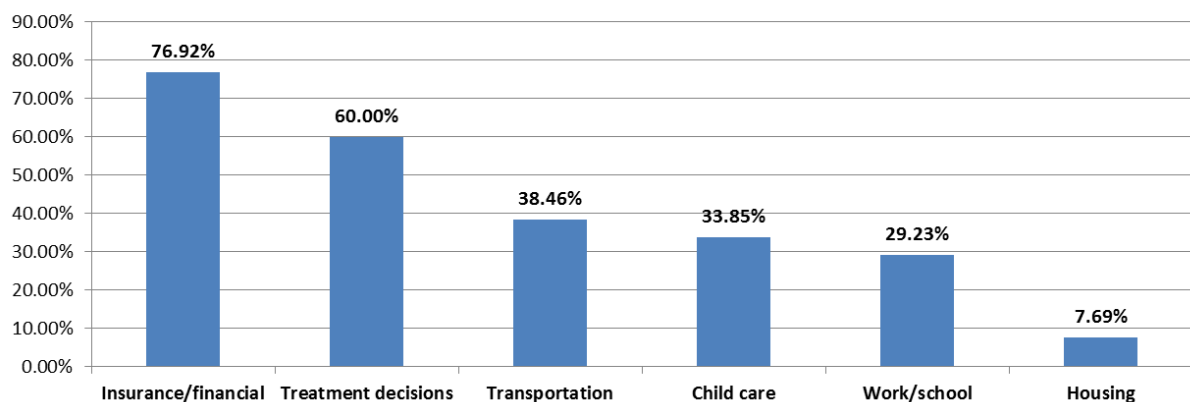


### Social (Continued...)

When asked what Practical Problems had the greatest need for support for breast cancer survivors:

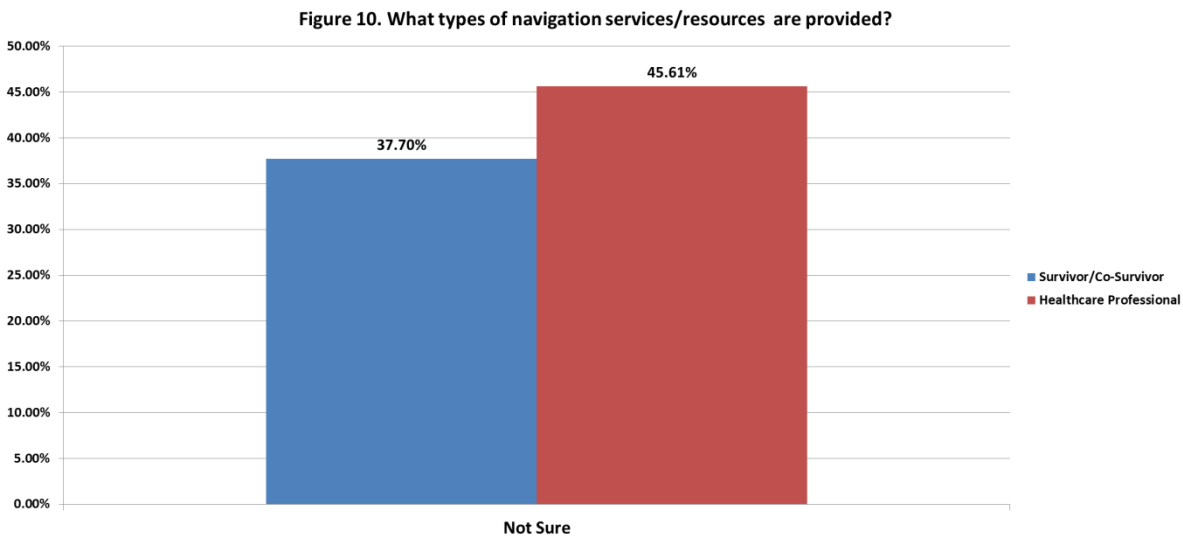
- 76.92 percent of surveyed survivors identified financial assistance and guidance, insurance assistance and affordable co-pays to be a practical problem of greatest need (figure 9).
- 38.46 percent of surveyed survivors found transportation to be a practical problem of greatest need (figure 9). 29.23 percent of survivors found work/school to be a practical problem of greatest need (figure 9) and the need for education on employment rights was discussed throughout interviews and discussion groups (figure 9).
- 29.23 percent of survivors found work/school to be a practical problem of greatest need (figure 9) and the need for education on employment rights was discussed throughout interviews and discussion groups (figure 9).
- In interviews and discussion groups with survivors, legal counseling on Advance Directives and Wills was discussed as a practical need that was not being addressed.

**Figure 9. In your community, which of the following PRACTICAL PROBLEMS have the greatest need for support in regards to breast cancer survivors?**



## Social (Continued...)

Lack of resources and knowledge of available resources for survivors and caregivers is a concern for survivors and co-survivors surveyed (figure 10).



- The lack of knowledge of services available to both survivors and their caregivers/families exacerbates the problem of there not being enough resources. 45.61 percent of healthcare professionals and 37.70 percent breast cancer survivors/co-survivors surveyed are not sure what navigation services or resources are available (figure 10).
- While healthcare professionals are generally aware of available resources, patients do not recall being communicated those resources.
- While there are quite a few support groups available in Jefferson County and one (1) in Shelby County, none were identified in the more rural areas.
- There is a lack of resources dedicated to caregivers and families, in all counties.

Studies have shown that cancer patients and their caregivers react to a cancer diagnosis as one emotional system. Caregivers often report as much anxiety and depression as the survivors themselves. Problems can occur when caregivers and survivors hide problems and worries from each other. The physical well-being of caregivers is compromised because the lack of time to rest or take care of themselves (Northouse et al. 318)

*“Hospitals can accommodate a lot, but many patients cannot afford the services. There needs to be some way to curtail cost. What happens to the person once they can’t afford to receive services anymore? Depression, anxiety, they become another statistic because they have nowhere to go. There are a lot of things I would like to do, but cannot afford.” -Survivor*

## Spiritual/Cultural

Spiritual needs ranked highly on the surveys, but were rarely mentioned in the interviews or discussion groups. This seems to indicate that the spiritual needs of survivors are being met in some other capacity. Places of worship provide avenues to disseminate educational materials and survivorship resources. A study of breast cancer survivors suggests that those who are less spiritually involved before their diagnosis, and who attempt to mobilize spiritual/religious resources after their diagnosis, may experience struggle and doubt that can impact their long-term adjustment. Unmet spiritual needs, including negative religious coping, have been associated with poorer quality of life for survivors (Peteet et al. 281).

The need for cultural sensitivity was frequently brought up in discussion groups and interviews particularly within the lesbian, gay, bisexual, and transgender (LGBT) community. Creating safe environments for LGBT survivors to disclose their sexual identity could improve cancer survivorship delivery as well as quality of life (Kamen et al. 50).

*“There is a trend amongst LGBT caregivers and survivors to veil/conceal their sexual orientation/relationship status from healthcare professionals, out of fear of discrimination.” - Discussion Group Participant*

## Conclusion

As early detection and treatment options improve, the number of breast cancer survivors will continue to increase and we will have the unique opportunity as a community to address the long-term health and rehabilitation needs of breast cancer survivors. Instead of addressing these needs individually, a comprehensive approach to the continuum of care can improve the quality of life of breast cancer survivors and their families.

This report identifies specific gaps in the continuum of care in each of the five (5) counties such as limited access to services and clinics. It also presents numerous opportunities to improve awareness about breast cancer survivorship resources. Furthermore, there are many opportunities to support breast cancer survivors during their most challenging struggles regardless of where they are geographically located and whether that time falls inside regular business hours. The challenge is how to raise awareness and educate survivors and co-survivors about breast cancer survivorship services, make use of existing programs and facilities that can meet their needs, and prioritize the investment of resources in new services. Initial recommendations include:

- Establishing a lay navigator system for breast cancer survivors
- Developing a centralized repository of breast cancer services and resources
- Providing a volunteer peer-to-peer support network
- Delivering telephone support to breast cancer survivors 24 hours a day, 7 days a week

The continued commitment of the five (5) major health systems in the greater Birmingham metro area to work together in addressing these recommendations is key. Through this collaboration the community will continue to develop a comprehensive program that will meet the needs of breast cancer survivors and their families in greater Birmingham; one that could potentially be replicated in other communities or for other cancer types and diseases.

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COMMUNITY FOUNDATION  
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